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ABSTRACT

Youth advocacy is the topic of the fourth in a series of four booklets. Set fourth in an introductory section is basic information about retardation and the role of an advocate. Selections from a diary of one adolescent advocate and the transcript of a taped interview with another are provided to illustrate the practical issues, frustrations, and rewards involved in the program. (CL)

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YOUth as a Citizen Advocate

U.S. DEPARTMENT OF HEALTH
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

Avenues To Change

Book IV

2

ED 117882

YOUth As A Citizen Advocate

BOOK IV

This series of materials was developed in conjunction with the NARC Project **A National Citizen Advocacy Model for Mentally Retarded Children,** Grant #OEG-0-72-5311, which was supported jointly by the Bureau of Education for the Handicapped, National Institute of Mental Health, and Rehabilitation Services Administration of the United States Department of Health, Education, and Welfare.

National Association for Retarded Citizens
February, 1974

BOOK IV

TABLE OF CONTENTS

I. Introduction
(Setting the stage) 5

II. Diary of a Youth Advocate
(Getting into Jan's head) 14

III. Interview with a Youth Advocate
(Rapping with Stan) 31

We wish to express our appreciation to members of Youth NARC's Task Force on Citizen Advocacy, NARC Youth Consultant Tom Johnson, and other Youth NARC reviewers who assisted NARC's Child Advocacy Project staff in the development of this book.

This book is **NOT** about a dry, academic theory called "Citizen Advocacy". It IS about the concept, the people, and the action that those two words represent.

This book is **NOT** about impersonal, faceless beings called "advocates". It IS about Stan and Janet and other individuals like them who are trying to do something to enhance the lives of mentally retarded people.

This book is **NOT** about stereotyped, retarded "proteges". It IS about Lori and Howie and other mentally retarded persons like them who are able to share in the benefits of the advocacy experience.

And, as you may have gathered, this book is **NOT** about labels. It IS about people . . . people who happen to be young . . . people who happen to be mentally retarded.

* * *

You have probably heard or seen the word "advocacy" used in many ways during the last few months; and generally speaking, it means "pleading another's cause". A lawyer is an advocate; Ralph Nader is a consumer advocate; parents are usually advocates for their children; Associations for Retarded Citizens are considered corporate advocates; there are also some government-supported programs today which are called Child Advocacy.

In this book we are talking about one specific model of advocacy called "Citizen Advocacy" which was developed by Dr. Wolf Wolfensberger. Citizen Advocacy has become more than just a concept made up of words written down on paper — it's a growing movement composed of advocacy programs across the country which are putting the plan into action. You as a young person can take part as a Youth Advocate.

We define Citizen Advocacy for mentally retarded persons as **"a one-to-one relationship between a mature, capable volunteer ("advocate") and a mentally retarded person ("protege") in which the advocate defends the rights and interests of the protege and provides practical or emotional back-up (or a combination of both) for the mentally retarded person. All of this occurs within the framework of a structured advocacy system.**

"A ONE-TO-ONE RELATIONSHIP": This simply means that two people meet on an equal basis in order to form a mutually beneficial relationship which involves sharing and accepting a certain amount of responsibility on the part of both parties. It does **not** imply that the advocate comes to the relationship with the following attitude: "I am going to be your advocate and help you whether you like it or not because my ego demands that I see myself as a benefactor going through the world shedding sunshine and doing good." In a true advocacy relationship, the protege has a great

5

deal to offer, too, and the relationship becomes a meaningful growth experience for both parties.

"A MATURE, CAPABLE VOLUNTEER ("ADVOCATE"): The words "mature" and "capable" used here refer mainly to emotional and mental maturity and capability. Teenagers make good advocates for proteges of all ages, and the major limitations placed on young teens are due to the fact that they have not yet reached the age of "legal maturity or accountability" and, therefore, may need some

assistance in matters requiring that the advocate be legally classed as an adult. But as a teenager "comes of age", he can add new responsibilities to his advocacy role.

When it comes to being advocates, young people have many qualities that give them an advantage over adults. While you as a young person and a novice advocate may not possess all the knowledge of bureaucratic systems or know-how to "go through channels", you do have impatience with these procedures, lots of energy, and the ability to think logically. Add idealism, human trust, and the willingness to get personally involved, and you have the makings of a Grade-A advocate. Information about systems, programs, and avenues of help open to your protege can be easily gained from the advocacy office, the Association for Retarded Citizens, or the Youth ARC. That's part of their role.

In an article entitled "Youths as Advocates" written by Donald Cohen and Catherine V. Richards for **Children Today** magazine, the following description of an advocate was given:

> **The advocate is skillful in working with available resources, but equally important, he is able to mobiiize new resources. He is able to keep his eye on the eventual target but to detour, accept frustrations, and tolerate delays as he progresses toward his goal. Effective advocates are not those who accept the status quo; rather they are assertive, competitive, and able to respond to a setback with a new, more forceful plan of action. And they are not detached — they function most successfully when they are deeply committed to their cause . . . In the process of thinking about and speaking for causes and other people, a young person may test his own beliefs and values, define his personal strengths, and shape himself into the kind of person that he admires. As he speaks for others, a youth brings his own values into sharper focus.**
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> **Children Today**
> **March-April, 1972**

Don't let the word **"VOLUNTEER"** in our definition throw you. The Citizen Advocacy Program is not just another stereotyped volunteer program. There are several elements which make advocacy different from traditional "Buddy" programs.

1) In the first place, the advocate is a volunteer to a specific individual, not to an institution, program, or agency. He doesn't just have contact with his protege in group settings or set visiting hours. He is **there** at all times if the protege needs him. He does not encounter the conflicts of interest which sometimes arise when a salaried professional must choose between what is best for the retarded person, and what is best for the agency he works for.

2) The advocacy relationship is a mutual one; it's not just one person condescending to help someone less fortunate than

7

himself. There's no pity involved. Advocacy is a two-way street.

3) In the past, it has been common for many youth volunteers to go into programs simply to bring recreation and enjoyment to mentally retarded persons. The scope of the advocacy program goes beyond this goal. Advocates want to establish friendships with retarded people, but they also want to work toward more community acceptance and a more normal lifestyle for their proteges. The advocate is a fighter for the rights, human dignity and individuality of his protege and tries to help the retarded person fulfill his potentials.

4) While there is a framework to the Citizen Advocacy Program (see discussion below), it is not as regimented as many volunteer programs. The advocate is initially screened and trained, and the advocacy office keeps in touch with him after he has been matched with a protege to make sure that things go well with the relationship. But, the advocate is not required to do a great deal of paperwork, and he is free to use his own creative ingenuity in devising ways to improve the quality of life for his protege.

5) While many volunteer programs, especially those which serve residents of institutions, are oriented toward short-term relationships and group activities, the advocacy program is geared toward establishing relationships that will be long-term whenever possible, and toward individualized attention for mentally retarded people.

"A MENTALLY RETARDED PERSON (PROTEGE)": A mentally retarded person is one of more than six million Americans (or roughly three percent of the total U. S. population) who will, at some time in their lives, function in the mentally retarded range. They are slow or limited in their learning processes, and may not be able to easily apply what they learn to daily living. Mental retardation is not the same as "mental illness" which is a mental disturbance that causes a person's inability to cope with his environment, regardless of his intellectual level.

Mental retardation is not a sickness, and retarded people should not be treated as "patients". Neither are mentally retarded people "overgrown children". They grow up just as we all do, but at their own particular rate with their own set of potentials. And they are not to be viewed as "sub-human" or "menaces to society". They are people like us with their own strengths and weaknesses.

Although we are trying to learn to stay away from labels and pigeonholes for people, it is necessary that you understand some terms commonly applied to the various levels of mental retardation so that you will know what they mean when you hear them. Basically, mentally retarded persons are divided into these "categories":

1) **Mildly Retarded** — This is the group with the least de-

gree of retardation. They are often not spotted as mentally retarded until they start to school where they are sometimes placed in special education classes. With the proper education and training, these people can live independently in the community with only occasional help.

2) **Moderately Retarded** — This group needs special education and vocational training to live semi-independently in the community in group homes, apartments, etc. Some will work in the community, while others will do better in sheltered workshops.

3) **Severely Retarded** — This group is capable of learning basic self-care such as eating or grooming, and most of the individuals can work productively in supervised settings. They can live in the community with ongoing assistance.

4) **Profoundly Retarded** — This group, which includes only about 1½ percent of all mentally retarded persons, has the most marked degree of retardation, but contrary to many generally accepted myths, they, too, can learn basic self-help through highly skilled training.

There are over 250 known causes of mental retardation, but in the majority of cases, the causes are still unknown, and, of course, much research in this field is going on now. Included in the list of causes are: poor pre-natal care for the mother; use of drugs or exposure to radiation by the mother during pregnancy; hereditary factors; accidents to or illness of the young child; malnutrition; severe environmental deprivation; and lead poisoning, often caused when children in poverty areas peel and eat flakes of lead-based paint off tenement walls.

Some mentally retarded people also have associated physical conditions such as cerebral palsy or epilepsy, and your protege may have such a handicap. The advocacy office, however, makes every effort to find out beforehand what your feelings as a prospective advocate are concerning having a protege who is multiply handicapped.

There are **three main groups** of retarded people who need advocates:

1) Those in institutions who need more individualized attention and someone to care about their rights and welfare.

2) Those leaving institutions to make the often difficult adjustment to life in the community. Trends today are toward deinstitutionalization or making it possible for more retarded people to live in the community. They need someone to help them bridge the gap.

9

3) Those who have always lived in the community, but are still isolated from people, especially of their own age who could provide valuable peer-group experiences.

"DEFENDS THE RIGHTS AND INTERESTS OF THE PROTEGE": Your role as an advocate will depend a great deal on the individual needs of the protege you are matched with. Advocacy roles range from being a Stand-by Advocate who helps a retarded person out of a jam in an emergency, to being a friend or an adviser to a protege over a long period of time. Included in Citizen Advocacy roles for adults are the more formal, legal arrangements like being a guardian or a trustee. When you come of age legally, you may want to expand your advocacy responsibilities in these directions.

The following are examples of roles Youth Advocates can play:

A female Youth Advocate to a mentally retarded, blind and deaf child must find a meaningful way to communicate with him.

A 16-year-old retarded girl with emotional problems runs away from home and is being held in the county detention center. Her parents, frustrated and angry with her behavior, refuse to allow her to return home. Her Youth Advocate is called in to work with the girl and her parents and the local advocacy office.

10

A Youth Advocate for a small, retarded child, realizes that the substandard housing the family lives in is hazardous to the health of the protege so he sets about to locate better living quarters for them, working with a service agency in his town.

A young man becomes an advocate for a middle-aged retarded man who cannot drive and has had no way to get out into the community for recreational or learning activities.

A girl decides to become an advocate and is matched with a retarded girl her own age who has cerebral palsy and has had no experience with peer-group friendships with normal girls her own age.

These situations are based on real advocate-protege relationships and illustrate the variety of ways youths can serve as advocates, going beyond mere leisure-time recreational relationships. They describe some of the ways a Youth Advocate can provide "PRACTICAL OR EMOTIONAL BACK-UP (OR A COMBINATION OF BOTH)" for the protege.

"THE FRAMEWORK OF A STRUCTURED ADVOCACY SYSTEM": This refers to the way in which several Citizen Advocacy programs have been implemented around the country thus far, and the way in which NARC is proposing that ARCs set up programs. While it is possible for advocacy relationships to happen without this office framework, it is felt that in order to have the most stable, lasting relationships and in order to provide back-up for the advocate, local and state advocacy offices are needed.

At the local level, the advocacy office will probably be started by the local ARC whose Board of Directors will serve as the policy-making body for the office. If at all possible, the local advocacy office should have a **full-time salaried** coordinator with secretarial back-up. The coordinator is responsible for recruiting advocates and proteges into the program through publicity, speaking engagements, etc.; screening applicants; training advocates; monitoring the advocate-protege relationships; and documenting and evaluating the success of the program. It is also helpful to hire a full-time or part-time assistant coordinator who may be designated as the Youth Coordinator to work specifically with the youth component.

The local office should also have an Advisory Committee made up of community professionals and interested laymen who serve as resources for the advocacy office. The membership can include lawyers, business leaders, city officials, teachers, physicians, social workers, clergymen, and representatives from various civic clubs or sister organizations for handicapped people. Members of the Advisory Committee can be called upon for advice and assistance when specific situations arise which fall within their areas of expertise. This gives you an opportunity as a Youth Advocate to work with adult professionals and make valuable contacts with them.

If there are several local advocacy offices established in a state, or if several programs are anticipated, it is best for the State ARC to establish a state advocacy office, too. This office reinforces its local branches by keeping informed about current legislation affecting handicapped people, serving as a research center for advocacy materials, organizing fund-raising efforts, disseminating publicity about local programs, providing legal back-up, training local coordinators, and generally coordinating the efforts of local advocacy programs.

The state advocacy office can also keep in touch with NARC's Child Advocacy Project, sharing reports and materials with NARC who will, in turn, send Citizen Advocacy materials to them. NARC's Project is a four-year federally funded effort to develop printed and audio-visual materials on advocacy to help ARC's set up programs and train coordinators and advocates.

WHAT ADVOCACY CAN DO FOR YOU, AND WHAT YOU CAN DO FOR ADVOCACY —

So far, we have talked about what Citizen Advocacy is, and who and what it involves. Reasons for involvement are apparent:

As an advocate, you can help a mentally retarded person grow and develop by giving him a more normal environment in which to live. Mentally retarded people have been isolated and over-protected for too long. They need to be exposed to experiences, both good and bad, that all of us have in common — happiness, fulfillment, rejection, failure. This is in line with the Normalization Principle you will study in your advocacy training sessions.

As a Youth Advocate, you can be more than a friend to your protege — you can speak out for his rights and make sure he receives all the benefits and services he is entitled to. You can help him to develop qualities that will enhance his social acceptability, and you can introduce him into the community in new ways.

You will enjoy the personal satisfaction of watching your protege gain a sense of his own value as an independent human being. You will also come to have a better understanding of the problems of retarded people as you make a service contribution that goes well beyond traditional volunteerism.

You will gain a new friend to get to know and have fun with.

You will be getting in on the ground floor of a nationwide advocacy movement that is spreading social activism. You can learn firsthand about human problems, and programs offering solutions. If you are considering a career in a related field, this experience will help you to make up your mind.

In conclusion, let's share this quote from the **Children Today** article mentioned above:

> **The society must clearly make evident its needs for the energies and abilities of youth. These needs should be significant to the society, call upon the talents and energies of young people, and provide youth with real experiences with the difficult policy issues involved in deciding the course of human affairs in their community. The profound questioning and occasional activism that marks advocacy by young people may arouse strong feelings in adults and their institutions. . . . The willingness of adults to respond to young people with honesty and flexibility is essential if young people are to develop into fully mature adults and skilled advocates.**

WANT TO KNOW MORE ABOUT CITIZEN ADVOCACY? READ ON!

The next two sections of this book deal with some of the more personal aspects of the advocate-protege relationship and should give you more of an idea what to expect . . . So, without further delay, we will introduce advocates Stan and Janet, and their proteges Howie and Lori.....

MY DIARY

March 31--Today is my seventeenth birthday, and tomorrow is another very important day in my life because I am going to take my final driver's ed. exam, and if I pass, I get my driver's license! I have been taking a special driver's ed. course after school for several months now, and I have a learner's permit which tomorrow will become a real driver's license.

It has been a lot of work, but my older brother Alan has helped me, and when he buys his new car, I will get the old Chevy.

And another important thing is about to happen in my life. Day after tomorrow I start in the local Youth NARC Chapter's Citizen Advocacy Program. That's a lot of words, but mainly it means that I'm going to be an "advocate" for a mentally retarded friend ("protege") and try to make her life better as we get to know each other and be friends.

I guess in this first entry, I should tell you a little about myself. As I said, I am 17 today and I have a 19-year-old brother who goes to college, and a 10-year-old little sister, Susie, who is a brat most of the time, and I live with my parents in I guess what you would call an average neighborhood. Our house looks like a used car lot since all of us, except Susie, of course, have, (or will soon have!) our own cars.

I am a junior at Thurston High School, and I make mostly B's and some A's, and I like English and think I might like to major in special education when I go to college. I am not as good in math and science, but Alan is, and even though he lives in the dorm at the college here, he still comes over to the house and helps me with my homework sometimes (when he isn't feeding his face!). I think going to college and living in a dorm will be neat.

Oh, yes, I should tell you, I have a boyfriend. His name is Stan, and he is a junior, too, and we have been dating about three months. We met in my Spanish class, and he has his own car (it's pretty beat-up, but we like it), and he is on the track

team, so we are enjoying the track meets this spring.

Stan and I really have a lot in common, and when I get assigned to my protege, we will have that in common, too. You see, Stan was the one I first heard about the advocacy program from. Several months ago, he saw a newspaper story about the program, and after asking for more information, he decided to volunteer. His protege's name is Howie, and what a cool guy he is! He is 25 and lived in an institution most of his life, but has recently moved into his own apartment, and has a job as maintenance man for an office complex. I have gone with Stan to see him a few times, and we have had a lot of fun. He has this wild sense of humor, and we laugh until our sides hurt. Stan has given Howie a chance to get out and do more things than he ever did before.

Well, I have to go and eat birthday cake and open some more presents. Susie insisted on giving me this diary first, so I could write in it before I got involved with all the other gifts.

April 1--I PASSED! and I am now a full-fledged driver. Daddy is going to take me out in Alan's Chevy and let me show him how good I am. Alan called to congratulate me, and says he has almost enough money to buy the new car he wants. I think I may try to talk Daddy into painting the old Chevy bright yellow when I get it.

April 2--Wow, so much has happened! Today I drove down to the advocacy office with my best friend, Sharon, and we signed up. Stan had already told the local coordinator, Mrs. Ashley, about me, and I knew a little about advocacy because of him and because of the Youth ARC kids who put on a school assembly about Citizen Advocacy.

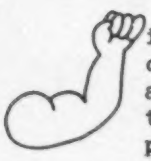
Sharon and I were kind of nervous, and we giggled a lot, but we did manage to fill out application and reference forms, and go through the interview. It really wasn't bad at all--not nearly as scary as the driver's test! Mrs. Ashley gave us some printed information on what Citizen Advocacy involves and said that now Sharon and I and the office will all have time to think it over before we go into the program.

After we are accepted, we'll be trained in orientation sessions and then we'll be matched with our proteges so we can start doing things and going places together. I realized today that I have really never had contact with many mentally retarded people before. I remember when I was little, and we lived in a different part of town, I used to laugh with all the other kids at this little boy on our block who was retarded. We thought it was really funny to run up to his yard and make faces at him through the fence.

And then there was this girl Alice who was in my sixth-grade class. She was slow in school and she wore very thick glasses. She was a couple of years older than the rest of us because she had flunked twice Finally, her parents put her into a special school somewhere because they all decided that she was "mildly retarded".

Now that I'm older, I look back and I can see how cruel we all were for making fun of kids just because they were different from us. Maybe if we had given them the same chances the rest of us had to be friends and learn how to get along, they would have turned out to be much more like us than we thought.

April 9--Today Sharon and I found out that we have been accepted as advocates, and Stan won a first place at the track meet, so it was a good day all around. Not much else happened this week. My grades slipped some during the last six weeks, and my running around has been cut down in favor of more studying. This is really a shame since I have my driver's license now, but if I can get my grades up, I'll be off probation before you know it.



The next step in being advocates is to go to two initial training sessions, one tomorrow night and one a week later, to learn about mental retardation and about our proteges. I am really looking forward to it, and Stan thinks it's great that I'm in the program now, too.

April 10--I am pretty tired tonight, but I wanted to write down a few of the things we heard in the training session to help me remember them for the future.

1) Citizen Advocacy is basically a one-to-one

relationship between a volunteer advocate and a mentally retarded protege where the advocate is not only a friend to the protege, but also looks out for his interests and helps him learn to do things that make his life richer.

2) There are three main groups of retarded people who need advocates: those in institutions, those leaving institutions to adjust to community life, and those who have always lived in the community. My protege can be from any one of these three groups.

3) The local advocacy office and the coordinator are always ready and willing to help the advocate help his protege. The office has an Advisory Committee made up of community professionals like lawyers and doctors and other interested people who can help solve problems, both for the office and the advocates. I found out tonight that my doctor, Dr. Robertson, is on the Committee. Our local advocacy office is part of a network of local offices all across the state which are coordinated by a state office. There is also a National Advocacy Project at the National Association for Retarded Citizens in Arlington, Texas, and Mrs. Ashley gave us some of their materials tonight.

April 17--Two important things happened today--Stan asked me to go to the Junior-Senior Prom with him, and I went to the second advocate training session. Maybe I will be able to take my protege shopping with me for my prom dress sometime before the dance in June. Tonight we learned more about mental retardation - its definition, causes, and levels, misconceptions concerning retarded people, and new trends toward helping them lead fuller lives. We learned that today the trend is toward getting as many retarded people as possible out of institutions and into community-based programs. And we learned that retarded people should be exposed to a full range of feelings and experiences, and they should have as normal an environment as possible.

I have certainly learned a lot so far, and next week I get to meet my protege for the first time.

April 25--Today I got my report cards, and my grades were much better, so I am not in the doghouse anymore. I had a meeting with Mrs. Ashley today, too, and she introduced me to my protege's parents and to a social worker who is assigned to her case. They wanted me to know more about my protege before I meet her for the first time on Saturday.

Yes, my protege is a girl, and her name is Lori Baker. She is two years older than I am although they say she acts younger. Her parents aren't ARC members, but they saw a newspaper story about the advocacy program and called the office. Lori is moderately retarded, but she also has epilepsy which they can control pretty well with medication. They told me all about what to do if she ever does happen to have a seizure when I am around, however. I am supposed to loosen all tight clothing, and try to prevent injury from falling or hitting nearby objects. I have her parents' phone numbers at home and work as well as Mrs. Ashley's numbers, and I have a medication schedule, so if we are out together when she is supposed to take medicine, I won't forget. It makes me a little nervous, but I think I can handle things, now that I sort of know what to expect. Her parents tell me that she isn't very friendly at first, and that she is shy, but I am such a nut, I can probably change that pretty quick!

Sharon hasn't been assigned to a protege yet, and she is jealous. Lori lives only a few blocks from me, so I am going over Saturday to pick her up and go to the Dairy Queen for a Coke. I am a little scared because what if she doesn't like me? But we will see, I guess. I bet she will like my family. She is an only child, and went to a private school for mentally retarded kids, so she hasn't had much exposure to kids like me, and doesn't have many friends. I am looking forward to our having a good time together.

April 28--Well, everything went pretty well, I think, but she dressed kind of plain and too young for her age. I'll have to help her with that. Her mother doesn't seem to know much about teen-agers' clothes. Lori has light blonde hair, very fine and straight, and big blue eyes. She is very nervous, though, and jumped the first few times I spoke to

her. She didn't have much to say, but I had a feeling that she was glad to see me. Her parents introduced us, and then left us alone in her room.

I felt sort of awkward, but she started off by showing me some of her record albums and posters, and that seemed to ease the tension a little. Then we went for a ride to get a Coke. She was really impressed with my car (did I tell you that Daddy had the Chevy painted yellow after Alan turned it over to me?). Anyway, the thing she liked best was the radio. I turned it off once because I thought it was making her nervous, and she reached over and turned it back on. She also liked the seat belts. Evidently her folks don't often use their's. I just don't understand how people can ignore safety measures like seat belts or proper insurance coverage. We learned all about that in driver's ed.

Sometimes I have a little trouble understanding what Lori says, but she did try to respond to most of the things I asked her. Other than that, though, she didn't talk much, so I told her about school, and Stan and the prom. She lit up the most when I started talking about shopping for my dress for the prom, and about the band that would be playing. She really likes music.

When we got to the Dairy Queen, she didn't want to go in for a Coke, so I got them at the window, and we sat in the car and drank them and watched the kids go in and out. I saw a couple of my friends and one of the boys even asked who Lori was, and that made her blush. I didn't tell him she was my "protege"; I just told him she was a friend of mine, and he seemed to understand. We planned to get together again next Saturday to go shopping, and maybe get a hamburger (inside the Dairy Queen this time!); and when I took her home, she seemed a lot more relaxed and confident.

As a matter of fact, so did I! I think we will be good friends, but I have a lot yet to learn about Lori and about being an advocate.

May 5--When I went to pick up Lori again today, she had tried to fix her hair like mine--parted in the middle and curly, but since her hair isn't cut like mine, it didn't turn out too good. I didn't

know whether to try to do it over for her, or just to let it go. I finally decided to praise her efforts, and see if later I can't get her mother to let me take Lori to my beauty shop for an easy-care hairstyle.

We had so much to do today that we barely got it all in. The first thing she wanted to do was to go to the Dairy Queen so we went by there first, and she went in with me to get the Cokes, and I helped her count out the correct change. She really loves juke boxes, and I almost couldn't get her away from the one in the Dairy Queen when it was time to leave to go shopping for my prom dress.

I think Lori was a little bewildered at the shopping center at first, but she soon was helping me pick out formals to try on, and she even tried on a couple. In the end, we bought this beautiful pale orange formal for me, and I helped her buy a new blouse with some money her mother had given her. Lori was really pleased when one of the salesladies thought we were sisters! I am starting to sort of feel like she is my sister. And she was also extremely interested in how my mom's charge account works at the dress shop--I think I am being a very "normalizing" influence on Lori!

After shopping, we went by my house so Lori could meet my family (they all got along great!) and then we went to my friend Sharon's house to pick up Shar and her protege, Ann, to go to a party the advocacy office was giving for advocates and proteges. Sharon got assigned to Ann just a few days after I was matched with Lori. Ann is a 16-year-old black girl from Inwood State School, the residential facility for mentally retarded persons in our town. Many of the proteges in our local advocacy program are referred to the office by Inwood, and everyone says that it is one of the best institutions in the country. I have never been out there, but Mrs. Ashley says some of us will be going for a complete tour soon. Ann is a different individual from Lori in that she is more outgoing. In fact, she is almost overbearing at times, but Sharon and I think that it's just because she wants attention because she doesn't get much personal recognition at Inwood.

The four of us picked up another girl friend of Shar's and mine named Lupe who wants to be an advocate, too, and we all went to the party. After a few strained moments at the first when none of us knew quite what we were supposed to do, we all loosened up and had a really good time. Lori ended up as Record-Changer at the stereo, a position she particularly liked, and Ann danced and talked with everybody. She is a very good dancer and showed Sharon, Lori, Lupe and me some of her favorite dances. Stan and his protege were there, so he got to meet Lori, and they liked each other very much. Stan had to leave a little early because of his part-time job.

The big highlight of the event was meeting the newly-hired Youth Advocacy Coordinator, Mike Ellington. Mrs. Ashley decided that the local program was getting so big she needed an assistant, so Mike is going to be our Youth Coordinator, and is he ever sharp! Somehow we had all expected him to be a real "do-gooder" type, wearing a suit and tie and acting righteous. But Mike is something else! He is 23 and is working on his master's at the college here, so he will only be working part-time in the advocacy program. His hair is longer than my brother's, and he has a moustache, wears wire-rimmed glasses, and rides a motorcycle. He really seems to understand kids. Mike told us how we can contact him if we need to, and he met each one of us personally before the party was over. He also said he has worked with the staff at Inwood to plan a tour of the institution for all of the Youth Advocates. Ann really liked that, and, as they used to say, "a good time was had by all" at the party!

May 6--Well, Lori and I had our first "crisis point" today, if you can call it that. Yesterday when Sharon and I brought Lori home from the party, we also had Ann in the car along with two guys who are advocates and neighbors of mine. We had volunteered to drive them home after we took Ann to Inwood. The boys, Curtis and Jimmy, are both 15 and are really nice and a lot of fun, but I guess we were all being pretty noisy, and the boys do have sort of long hair. Evidently, Mr. and Mrs. Baker thought we were getting their daughter mixed up

with a wild crowd or something because they pounced on Lori with a million questions the minute she got in the door. She was still upset about it today, and called me, and started to cry. I guess she thought all her new friends were going to be taken away from her.

Well, I called up Stan (who has longer hair than either Curtis or Jimmy) and we went over to see Lori and her folks. By the time Lori's parents had talked to Stan for awhile, I think that they were convinced that just because those guys have long hair doesn't mean they're automatically rebellious or anything like that. Lori's folks told me later that they thought Stan was a "well-mannered, intelligent (good-looking!) young man with a lot on the ball". He told them all about his track interests, and his part-time job at the florist, and everybody was really impressed. We both casually assured them that long hair was just the style now, etc. So everything worked out fine. It all got me to thinking how people who expect kids with long hair to be bad are setting patterns of low expectations for these kids which could limit their motivation. This seems similar to me to setting low standards for mentally retarded people because by believing in and spreading destructive attitudes about them, people are restricting their potentials for development. That's a heavy thought. Anyway, it all worked out well in the end. I wish my parents could have been there!

May 14--I was sick in bed with the flu over the weekend so Lori and I didn't get to do anything together. Today when I was really feeling blue and wishing I was better, I got a card in the mail that Lori had made for me. It had pictures of flowers and a girl in a long dress and music notes pasted all over it and said, "Get Well Soon, Love Lori". You know, being an advocate is really a very nice thing!

May 19--Today was a day I'll never forget. Mike and Mrs. Ashley had arranged tours to the institution and a group home here for several of us Youth Advocates and some of the adult advocates in our local program. We went out to the institution first. Sharon and I had been out to Inwood before when we

took some of the kids home from one of the advocate-protege parties, but we had never been given a tour before, and for some reason, I felt sort of uneasy about the whole thing when we were driving out there.

As far as state residential facilities for the mentally retarded go, Inwood is supposed to be above average, but even though you can tell that they have tried to make the dorms and dayrooms look as cheerful as possible, the whole impression I got of the place is one of darkness. All the bright curtains and bedspreads in the world can't make one large room with 40 beds in it sitting on a cold tile floor in a very old barn-like building look like anybody's "home".

Mrs. Ashley explained to us how the institution has tried to develop programs which will help the residents, but there are so many of them and so few staff people that there is barely time to take care of the physical needs of the retarded people living there, let alone their needs for affection and activity. Sharon's protege, Ann, says that the worst part of living there is that there is nothing interesting to do. She works in one of the dorms, helping to take care of some of the smaller kids, but if it weren't for Sharon, she would never get a phone call or a letter or get to do all of the neat things they do together like shopping, or riding around, or just going for a walk in the park.

One of the bad things about Inwood is that it is located on the outskirts of town, so that it is not near any shopping centers or homes or anything. This means that when the residents do get to come into town, they have to ride on the bus that has "Inwood State School" painted all over the sides of it, and everybody automatically knows where they are from. This segregates them from the very beginning. They all do sort of look different from "average" kids, too, because most of them have very short, straight hair, and some wear clothes that look like somebody must have donated them to the institution. Of course, many of those who have parents in our town or nearby do have visitors pretty often and they have new clothes and things, but it seems to me that a lot of the residents just have nobody to

care anything about them. Several of them ran up to us and said "Hi" and grinned and seemed very glad to see us.

I also have a feeling that we didn't get to see all of the wards at Inwood. We never even saw Sharon's protege. Most of the kids we met were very young, but I am sure there are adults out there who have lived there all their lives and will continue to live there until they die--how frustrating and lonely it must be! Their lives are wasted, and I know from meeting many of the proteges in our program that they could do something if given half a chance.

The saddest thing I saw there was in a dayroom where one little boy was standing in a corner with his hands over his ears so he couldn't hear the noise of all the other kids around him, I guess. Mrs. Ashley told us that sometimes he just stands and bangs his head against the wall because there is nothing else for him to do. Another little girl had taken a shoe away from one of the other kids and was pushing it around the floor and pretending it was a car or a train because she didn't have any toys to play with. There are a few toys around, but the kids either fight over them, or the toys are kept on high shelves out of reach. It reminded me of Lori because she has a beautiful doll collection that her parents started for her when she was little, but those dolls just sit there and collect dust because they would never let her play with them; she could only look.

In contrast to Inwood was the group home for retarded girls that we visited. The girls call it Delta House, but there's no sign that says so, and from the outside, it looks just like any of the other homes in the neighborhood--a red brick building with several stories and a big front porch and lots of big trees around it. There are 12 young women living at Delta with two houseparents, a young couple who are really cool and certainly seem to be into getting to know and help the tenants of Delta House. The girls each have their own rooms, and they are fixed up real cute--one girl had a very feminine, frilly room, while another had mod post-

ers and a blacklight in her's. I think this kind of privacy is very important for any girl. They all share the housework, and almost all of them hold down some kind of job, either in the community or in the sheltered workshop in our town where retarded persons learn and do productive jobs. In contrast to the bare dayroom at Inwood, these girls have a warm, homey living room with a TV, a pool table, and other things to do--a place to bring their friends. You couldn't help seeing how happy they all seemed to be and how proud they were of their independence. Something like that would do Lori a lot of good.

May 30--Today I found out about the more serious side of being an advocate. I hadn't seen Lori for quite a few days because I have had final exams at school and have been pretty busy studying. About 5 p.m. this afternoon, Lori called me at home, and she was crying hard. She was at the hospital with her mom because her dad had had a heart attack and was in intensive care. Naturally, Lori was awfully shook up, so I asked her to put her mother on the phone and I managed to find out that it wasn't a massive coronary or anything like that, and that he was going to be all right. She put Lori back on, and after talking to her a while longer, I decided that even though her mom had told her that her dad was going to be O.K., she was still afraid that he wouldn't be. So, I changed clothes, called Stan and told him I was going to the hospital to see Lori because her father was there, and drove on over.

Lori and her mom were in one of the waiting rooms, and, of course, there were lots of her mom's relatives and friends around, so Lori and I went for a walk down to the coffee shop to get a Coke. She had calmed down a little, and after we talked a while, I think she felt much better. I just explained to her that, while heart attacks are always a serious matter, they aren't always fatal. I think the reason she was so scared was that she had seen a show on daytime television this summer where one of the guys had a heart attack and died, so she didn't understand that it wasn't going to be that way with her dad. About the time we were ready to go back upstairs, Stan walked into the lobby, and Lori was

25

really glad to see him. He put his arm around her shoulders and told her how sorry he was about her dad, but that he knew everything was going to be all right, and she seemed to believe him even more than she did me. After we walked her back to where her mother was, Stan and I decided to leave, and we both told Lori we would check in with her in the morning.

On the way back downstairs, Stan and I stopped off at the maternity floor and looked at the babies in the nursery. Stan and I have sort of joked about getting married someday, but we have never talked seriously about marriage or having children. We pretended that one of the babies was ours and kidded around about how much he looked like Stan, etc., and then he surprised me by saying, "You know, Jan, I always used to think that if I ever had a child that was retarded or handicapped in any way, I wouldn't want it, but after having known Howie and Lori, I've changed my mind. They have made me see that even if a child isn't perfect physically or mentally, he still has a lot to offer." That was all he said, but I was sure impressed. Isn't he great!

I will have to take Lori to see the new babies. She has been asking me some questions about boys and dating and marriage and babies lately, and I have tried to answer clearly and honestly. Maybe a visit to the nursery would give us a chance to talk about these things again.

May 31--Well, I never thought any day could be worse for Lori than yesterday was, but today, more trouble started. I called her this morning, and she was more cheerful. Then her mother asked to speak to me, and sent Lori out of the room, so I knew that something was up. It seems that Lori's mother has been so shaken up over her husband's attack that she has been forced into thinking about what will become of Lori when both of her parents aren't around any more. Mrs. Baker has never been very strong physically, and she is often sick, but now that the strong member of the pair is in the hospital, and will probably have to take it easier from now on, Lori's mother is wondering if it would be better to start trying to get Lori into Inwood now so that she will be taken care of after her

parents are gone. I can't tell you how upset it made me to think about Lori living out there. She has so much potential, so much to give! I could feel that several of Mrs. Baker's friends and relatives must be encouraging her toward this decision. I asked her if she had ever heard about group homes for retarded girls (like Delta House), and I told her all about how the girls there keep house and hold down jobs and live productive lives. Mrs. Baker sounded doubtful to say the least, but I did convince her to come down to the advocacy office and talk to Mike and Mrs. Ashley and some of the members of the Advisory Committee for the advocacy program. Then I called Mrs. Ashley and Mike and they said they would try to set up a meeting as soon as possible for Mrs. Baker with the houseparents of Delta House, Lori's doctor, and some of the appropriate professional people on the Advisory Committee. So, I am keeping my fingers crossed and hoping for the best.

Oh, yes, I almost forgot, in all this excitement, I didn't write down that I am out of school now, and got my final grades a couple of days ago. I did fine on all my final exams except algebra, but my average was so high for this semester that I made the honor role in spite of algebra. My folks are very pleased, to say the least, and they said I can give a backyard party for all my friends sometime this summer. But first, I have to help get this situation with Lori and her parents straightened out.

June 5--Well, a lot has happened, so I had better bring you up to date. The meeting with Mrs. Baker, Mike, Mrs. Ashley, the houseparents of Delta, and part of the Advisory Committee was held the first of the week, and it went very well. The members of the Committee who are involved in counseling and programming for retarded persons were encouraging, and Mrs. Ashley arranged a tour of Delta House for Lori and her mom and me yesterday. I finally persuaded Lori's mom to sit down and talk to Lori about the alternatives she was considering. I knew it would upset Lori some, but after all, she certainly has a right to help decide her own future! That's the problem with my protege--her folks have always protected her from everything, and haven't let

her make any decisions concerning her own life. Anyway, Lori took it all very well, and was excited about going to see Delta House. She doesn't know very much about Inwood, but she has evidently taken in enough of what Sharon's protege, Ann, has said about living there, that she isn't too crazy about the idea.

So, we went over to Delta yesterday, and Lori really fell in love with the place. As luck would have it, one of the girls who has been living there is leaving to get married, and the girls were giving a shower for her, so Lori and her mom got to see some of the social life of the place. I could tell that Lori's mother was still skeptical about Lori's ability to fit into such a place, so I encouraged her to sit down and talk with the houseparents while her daughter and I went up to see one of the girl's room. Judging from what Mrs. Baker said to me later, the houseparents told her the stories of two girls who had lived at Delta in the past, and had come there with much less going for them than Lori has in her favor, and they adjusted beautifully! So, now we will just have to wait and see what she and Mr. Baker, and Lori decide.

June 8--Two important things happened today. Mr. Baker came home from the hospital, and for the first time, I think Lori is really convinced that he will be all right.

And best of all, Mr. and Mrs. Baker have talked it over, and they have decided to go ahead with the procedures to get Lori into Delta House. Lori is both thrilled and somewhat frightened at the prospect, but I must admit that she has plenty of nerve because right after they told her, she went in and got her suitcase out and was ready to start packing. I don't think there's much chance that she won't get into Delta with all the back-up she's got from her family and me and the advocacy program.

June 22--This will probably be my last entry in this diary for a few days because my family is going to Colorado on vacation. I am looking forward to it, but I will certainly miss Stan during that week. I guess I can send him lots of postcards. And, of course, I will be writing to Lori, too, at her new

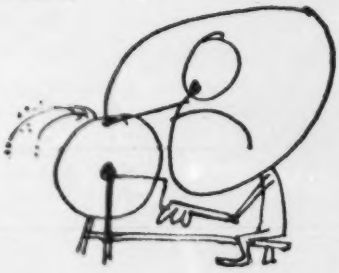
address. I helped her move the last of her things over to Delta House yesterday, and Mrs. Ashley and the houseparents are on the track of a job for Lori in the sheltered workshop where she can get training to go on and do regular work in the community later. When I got over to Lori's house yesterday, her parents were already over at Delta House making some arrangements, and I was supposed to bring Lori and the last load of her stuff on over when she was ready. She didn't answer the door when I rang the bell, but the screen was open, so I went on in. She was in her room which was pretty well stripped down by then, and she was sitting on the bare mattress with her head bent, her shoulders slumped, and her hands folded dejectedly in her lap. All that was left to be packed was her doll collection. "What is the matter?" I asked. She looked up, and I could tell that she had been crying.

"I'm not sure I want to go", she said. I started to tell her that was just plain stupid, and yet somehow, I understood, so I just bit back my harsh remarks, and said, "Well, it will be a big step for you, but I think you'll like being more on your own, and besides your parents and I will be close by, and you and I can have lots of fun shopping to fix up your room at Delta with the money you earn yourself at your job at the workshop. And we can sew new curtains when we take that sewing course at the community center next fall. And I need you to help me give a backyard party at my house soon, too!"

She brightened up at that, and looking at the doll collection, she said, "You know, I don't think I want to take all those dolls with me after all. I think I'll just take one of them and give the rest to you--maybe your little sister would like them." I told her that I thought that was a great idea, and that Susie would be thrilled. So, in a much happier frame of mind, we both carefully wrapped the dusty dolls in tissue paper and tucked them in a big cardboard box. I was interested to see which of the dolls she would save out to take with her, and she took a long time deciding. She passed over the baby dolls in their white smocks and bonnets, and all the foreign dolls, and the teenaged dolls in the pink organdy formals, and finally settled on an old rag doll that sat on the bottom shelf. "That was the only one I could really play with, and I even slept with it", she said. "I want to keep

29

it to remind me of the good times when I wasn't grown up", she concluded. And with that, we loaded up my car, locked the front door, and headed for Delta House with a stop on the way so Lori could give all those beautiful dolls to my little sister.



30

INTERVIEW WITH A YOUTH ADVOCATE

The following is a transcript of a taped interview between Assistant Citizen Advocacy Coordinator Mike Ellington and advocate Stan Welch concerning Stan's relationship with his protege, Howie Wilson. This was selected from the files as a good example of the practical aspects of Citizen Advocacy.

Date: **May 12**
Interviewer: **Mike Ellington**
Advocate: **Stan Welch**
Protege: **Howard Wilson**

Mike: Hi, Stan, come on in and sit down. Let me get the file folder on you and Howie. I'm really glad you could come down to the office today. Since I just started this job, I've been trying to meet all the Youth Advocates personally and get to know them and their proteges. Is Howie going to be able to come in with you on Tuesday afternoon?

Stan: Yes, no sweat. He says I can pick him up right after I get off work.

Mike: What kind of job do you have?

Stan: I drive a florist's delivery truck after school and on Saturdays making deliveries to hospitals and people's homes and so on.

Mike: Janet tells me you've been running track, too. With your schoolwork, you've got your hands pretty full.

Stan: Oh, it's not too bad. My job hours are flexible, and, well, most of my friends are just as busy, or busier than I am.

Mike: How long have you been Howie's advocate and how often are you two able to get together?

Stan: Oh, Howie and I started out eight months ago when he hadn't been out of the state school for very long. We see each other at least once a week, and if I can't get with him more than that, we call each other.

Mike: Tell me a little about Howie. Has he changed since you've known him?

Stan: You bet. When I first met Howie, he was really pretty obnoxious. Evidently, nobody had paid much attention to him when he was in the institution, so everything he did was a bid for attention, and he was very aggressive. Howie's mom died when he was very little, and his dad

has re-married and has a couple of small kids. He wants to take care of Howie financially, but doesn't care to have much to do with him otherwise. Howie was pretty insecure with me at first, but after he saw that I was going to stick around, he calmed down some, and his great sense of humor began to shine through. Howie may be mentally retarded, but he does lots of things well, and he's fun to be around. His hobbies are wood-working and music. He has accumulated quite a few tools and has the garage at his new apartment set up as a shop. He repairs things for his landlady and his friends, and makes toys for the neighborhood kids. He's also got a record collection that won't quit. Another thing — Howie throws a frisbee better than almost anybody I ever saw.

Mike: Does he talk much about what his life was like in the institution?

Stan: Nope, he always changes the subject when I ask about it. It's my personal opinion that Howie probably wasn't very retarded at all when he was placed in the state school. Maybe he was more of a behavior problem that his dad just couldn't handle after his mom died. Being in an institution certainly didn't improve him any. But, man, have we ever come a long way in the last few months!

Mike: In what ways?

Stan: Well, there were two major situations that we have worked out. You see, when Howie was first discharged from the state school, he was living with two other guys who had been out of the same institution for a few months, and they really gave him a hard time—made him do all the work around the apartment and just generally treated him like an inferior. He was still looking for a job then and only had a little money that his dad sent from time to time. Luckily, the people at the institution gave Howie's name as a referral to the local advocacy office, and I came on the scene. After Howie and I had gotten together a couple of times for a show or just to go riding around, we got into a serious rap about his living situation and his two crummy room-mates. He said if he could get a job, he would have the money to live on his own, so we started looking right then. Mrs. Ashley helped us find the job. One of the businessmen on the Advisory Committee interviewed Howie and hired him as a maintenance man for the office building he owns. It's really much more than a janitorial job, and Howie gets to use his carpentry skills and has an opportunity to learn about things like fuse boxes and elec-

trical wiring, too. However, there were a couple of problems with the job at first, but I'll tell you about those in a minute. Getting that job really gave Howie a boost and he started standing up to his room-mates and not letting them take advantage of him so much. I kept on encouraging him, and then my aunt told me about this friend of her's who had a garage apartment for rent, so Howie and I sat down and figured his budget and then went to look at the apartment. It's just right for him — he can keep his tools in the garage, and it has a kitchenette, so Jan and I have been teaching him how to cook. After he moved in, he and I also worked out the best bus routes for him to get to work, and now he can find his way around town real good.

Mike: What was the difficulty with the job that you mentioned earlier?

Stan: Well, when Howie first started to work, his supervisor was really trying to rook him. He was working him overtime every night and not paying him for it, and he had Howie doing errands and things for him that were outside of his job responsibility

Mike: This wasn't the same man who hired him, was it?

Stan: No, this was the supervisor. When I found out about the situation, I went straight to the man who had hired Howie in the first place, and you can bet he straightened out the situation plenty fast. The supervisor was replaced, and now Howie is getting a fair shake on his job.

Mike: That's great. What's your next project?

Stan: It's been real interesting for me to be Howie's friend. Everything is so new to him; it's like he's lived on another planet most of his life. One of our next goals is to shop for some new clothes for him. Now that he's let his hair grow a little and has money to spend on clothes, his appearance is much better. And he has decided he wants to vote in the next election, so we've been digging into politics. And then there's a course starting this summer at the community center on fly fishing — you know, how to tie flies and what gear you need and all that. We're both enrolling for that.

Mike: Sounds good. How do you feel in general about being an advocate?

Stan: Well, I have sure learned a lot and I have a much better understanding now of what it means to be a retarded per-

33

son. And like I said, Howie and I have a good time together. He loves to go to the movies, so we usually see a western or a science fiction flick on the weekend. He likes to walk around downtown and check out the girls, too.

Mike: I'll bet Janet isn't too crazy about that!

Stan: She's pretty cool about it.

Mike: What do you think of her being an advocate?

Stan: I am really pleased. I've met Lori, and I think they'll be good for each other. Jan and I are both considering careers in some field related to mental retardation, you know.

Mike: That's great! Maybe I've got some materials around here I can give you on that. Listen, if any problems come up, you know you can count on me or Mrs. Ashley to help. Im looking forward to meeting Howie on Tuesday. Stan, would you be willing to be on a panel of Youth Advocates who will speak to Civic Clubs and people like that who request programs on advocacy? Do you have time?

Stan: You bet! I'm really sold on the program and want to get others involved. Jan and I have been talking about writing a one-act play on advocacy. Maybe we could put that on for some club.

Mike: O.K. At the next meeting of all the Youth Advocates, let's present that idea to the group. I bet they'll dig it.

Stan: Right. Well, I've got to go. I need to do some jogging this afternoon.

Mike: Let's see if I can find those pamphlets on careers in the field of mental retardation . . . Here are a couple, and I'll see what else I can find by Tuesday.

Stan: I sure am glad they decided to hire you. Mrs. Ashley has needed some help, especially with us kids, and having a guy in the job will be great. I want to get more guys involved in the program. Too often, only girls get into programs like this, and there's a lot we males can do, too. Well, so long!

Mike: Bye Stan. See you and Howie Tuesday.

We hope that reading this book has given you a good introduction to Youth Advocacy and that hearing from Janet and Stan has made you think seriously about becoming part of the program.

How can **you** get involved, and find out more about advocacy? If there is already a Citizen Advocacy Program in your town, contact the local coordinator who can fill you in on the details and will have other materials on advocacy to give you.

This book is part of a four-book set put out by the National Association for Retarded Citizens' Child Advocacy Project. The other three books are available to you, and can provide you with in-depth information on the concept and how it works. Book I is an introduction to Citizen Advocacy; Book II tells how to start programs; and Book III is about effective advocacy. NARC also has other printed and audio-visual materials on Citizen Advocacy and mental retardation, and the address is:

NARC Child Advocacy Project
National Association for Retarded Citizens
2709 Avenue "E" East
Arlington, Texas 76011

If there is no advocacy program in your city, perhaps you can help get the ball rolling. Get into advocacy. Who knows how far

35

you can go. **You** can make it happen! Here are some action steps to get you started:

1) **Contact your local ARC or Youth NARC Unit and find out what is already being done about Citizen Advocacy in your community. If they haven't heard about the concept, share with them the materials you have received from NARC.**

2) **Talk with friends and fellow students about Citizen Advocacy and get a special interest group started.**

3) **Talk to your parents and any influential adults you may know in the community who might be able to help you.**

4) **Find out about programming for mentally retarded persons in your community and determine where Citizen Advocacy can fill a need.**

5) **Be persistent! Good luck!**

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36